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A CASE STUDY IN POLITICS AND SCIENCE
CHANGES TO THE NATIONAL HEALTHCARE
DISPARITIES REPORT

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EXECUTIVE SUMMARY

In March 2002, the Institute of Medicine found “overwhelming” evidence that racial and ethnic minorities suffer disparities in healthcare and concluded that “the real challenge lies not in debating whether disparities exist . . . but in developing and implementing strategies to reduce and eliminate them.” In the months that followed, the U.S. Department of Health and Human Services (HHS) was faulted for not pursuing many of the strategies recommended by the Institute of Medicine to counter healthcare disparities.

On December 23, 2003, HHS released its own long-awaited *National Healthcare Disparities Report*. Unlike the Institute of Medicine, however, HHS did not describe healthcare disparities as a national problem. In fact, the HHS report emphasized that in some ways racial and ethnic minorities are in better health than the general population.

At the request of Rep. Henry A. Waxman, Rep. Elijah E. Cummings, Rep. Ciro D. Rodriguez, Rep. Michael M. Honda, Del. Donna M. Christensen, Rep. Hilda L. Solis, Rep. Danny K. Davis, and Rep. Dale E. Kildee, this report investigates why HHS reached conclusions on healthcare disparities that differ from those of the Institute of Medicine. The investigation is based on a comparison of two versions of the healthcare disparities report: (1) the final version that was released by HHS on December 23 after review by political appointees in the Department; and (2) the draft executive summary that was prepared by HHS scientists and widely circulated in the Department.

The investigation finds that HHS substantially altered the conclusions of its scientists on healthcare disparities. In the June draft, the Department’s scientists found “significant inequality” in health care in the United States, called healthcare disparities “national problems,” emphasized that these disparities are “pervasive in our health care system,” and found that the disparities carry a significant “personal and societal price.” The final version of the report, however, contains none of these conclusions.

This investigation finds:

- **The final version of the *National Healthcare Disparities Report* deletes most uses of the word “disparity.”** The scientists’ draft defined “disparity” as “the condition or fact of being unequal, as in age, rank, or degree” and included the term over 30 times in the “key findings” section of the executive summary. By contrast, the final version leaves “disparity” undefined and includes it in the “key findings” section just twice.

- **The final version eliminates the conclusion that healthcare disparities are “national problems.”** The scientists’ draft found that “racial, ethnic, and socioeconomic disparities are national problems that affect health care at all points in the process, at all sites of care, and for all medical conditions — in fact, disparities are pervasive in our health care system.” The final version states only that “some socioeconomic, racial, ethnic, and geographic differences exist.”
- **The final version drops findings on the social costs of disparities and replaces them with a discussion of “successes.”** The scientists’ draft concluded that “disparities come at a personal and societal price,” including lost productivity, needless disability, and early death. The final version drops this conclusion and replaces it with the finding that “some ‘priority populations’ do as well or better than the general population in some aspects of health care.” As an example, the executive summary highlights that “American Indians/Alaska Natives have a lower death rate from all cancers.” The executive summary does not mention that overall life expectancies for American Indians and Alaska Natives are significantly shorter than for other Americans or that their infant mortality rates are substantially higher.
- **The final version omits key examples of healthcare disparities.** The scientists’ draft concluded that racial and ethnic minorities are more likely to be diagnosed with late-stage cancer, die of HIV, be subjected to physical restraints in nursing homes, and receive suboptimal cardiac care for heart attacks. The final version drops these examples. The report instead highlights milder examples of healthcare disparities, such as the finding that “Hispanics and American Indians or Alaska Natives are less likely to have their cholesterol checked.”

A previous report for Rep. Waxman by the Special Investigations Division documented a growing pattern of political interference with science at HHS and other science-based federal agencies.¹ The alterations made by HHS in the *National Healthcare Disparities Report* provide another example of the increasing politicization of science under the Bush Administration. In this case, the changes to the National Healthcare Disparities Report minimize the scope and extent of racial and ethnic disparities in healthcare, undermining efforts to address these problems.

¹ Minority Staff, Government Reform Committee, *Politics and Science in the Bush Administration* (Aug. 2003) (online at www.politicsandscience.org).

INTRODUCTION

On March 20, 2002, the Institute of Medicine published a landmark report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care*. Dr. Alan Nelson, the chair of the committee that produced the report and former president of the American Medical Association, summarized the report's key findings: "Disparities in the health care delivered to racial and ethnic minorities are real and are associated with worse outcomes in many cases, which is unacceptable.... The real challenge lies not in debating whether disparities exist, because the evidence is overwhelming, but in developing and implementing strategies to reduce and eliminate them."²

The Institute of Medicine report made a number of recommendations for action to reduce healthcare disparities. As months passed, however, criticism mounted that the U.S. Department of Health and Human Services (HHS) was not pursuing these changes. On June 24, 2002, eight members of Congress wrote HHS Secretary Tommy G. Thompson to note several contradictions between the advice of the Institute of Medicine and the actions of the Department. These included:

- Despite the Institute of Medicine recommendation to "increase the proportion of underrepresented U.S. racial and ethnic minorities among health professionals," the Administration's fiscal year 2003 budget proposed the elimination of three programs that serve this goal: the Health Careers Opportunity Program, the Minority Faculty Fellowships Program, and the Centers for Excellence Program.
- Despite the Institute of Medicine recommendation for "further research to identify sources of racial and ethnic disparities and assess promising intervention strategies," the Administration's Fiscal Year 2003 budget proposed cutting a major HHS effort to reduce disparities, the EXCEED program, by 25%.
- Despite the Institute of Medicine recommendation that government programs should "avoid fragmentation of health plans along socioeconomic lines," HHS weakened protections for Medicaid patients in HMOs and dropped a prohibition on discrimination by HMOs against Medicaid patients.³

² Institute of Medicine, *Minorities More Likely to Receive Lower-Quality Health Care, Regardless of Income and Insurance Coverage* (Mar. 20, 2002).

³ Letter from Rep. Henry A. Waxman et al. to Secretary of Health and Human Services Tommy G. Thompson (June 24, 2002).

At the same time that HHS came under this criticism, Department scientists were conducting their own research on healthcare disparities. As part of the Healthcare Research and Quality Act of 1999, Congress had directed the Agency for Healthcare Research and Quality (AHRQ) to issue an annual report that tracks “prevailing disparities in health care delivery as it relates to racial factors and socioeconomic factors in priority populations.” During 2002 and 2003, HHS scientists worked to draft the first of these reports. As the Institute of Medicine advised the Department in September 2002:

The National Healthcare Disparities Report could play a major role in raising awareness of racial, ethnic, socioeconomic, and geographic health care disparities. It could also help to guide Congress and other policy makers in areas that require action to eliminate disparities.⁴

Responsibility for the report was divided within HHS. According to information provided at a congressional briefing, scientists at the Agency for Healthcare Research and Quality took the lead in developing the science, drawing on experts from the National Institutes of Health, the Centers for Disease Control and Prevention, and other health agencies. The final report was then coordinated and overseen by political appointees at HHS, including by the office of the Assistant Secretary for Planning and Evaluation.

On December 23, 2003, after Congress had adjourned for the year, HHS finally released the first *National Healthcare Disparities Report*. The report’s conclusions differed markedly from those of the Institute of Medicine. Unlike the Institute of Medicine report, the *National Healthcare Disparities Report* released by HHS did not describe healthcare disparities as a national problem. In fact, the executive summary of the report seemed designed to minimize the significance of healthcare disparities, even incorporating a new section on “successes” that emphasized instances where “priority populations” received superior healthcare.

Rep. Henry A. Waxman, ranking member of the Government Reform Committee, Rep. Elijah E. Cummings, chair of the Congressional Black Caucus, Rep. Ciro D. Rodriguez, chair of the Congressional Hispanic Caucus, Rep. Michael M. Honda, chair of the Congressional Asian Pacific American Caucus, Del. Donna M. Christensen, chair of the Congressional Black Caucus Health Braintrust, Rep. Hilda L. Solis, chair of the Congressional Hispanic Caucus Health Task Force, Rep. Danny K. Davis, secretary of the Congressional Black Caucus, and Rep. Dale E. Kildee, Democratic co-chair of the Congressional Native American Caucus, asked the Special Investigations Division of the minority staff of the House Government Reform Committee to investigate the preparation of the

⁴ Institute of Medicine, *Guidance for the National Healthcare Disparities Report* (Sept. 2002).

National Healthcare Disparities Report. In conducting the investigation, the Special Investigations Division obtained a draft of the report's executive summary that was written in June 2003 by HHS scientists and widely circulated in the Department.⁵ The Special Investigations Division reviewed both the scientists' draft and the final report and compared their key findings. This report presents the results of this investigation.

FINDINGS

The investigation finds that HHS substantially altered the conclusions of its scientists on healthcare disparities. In the June draft, the Department's scientists found "significant inequality" in health care in the United States, called healthcare disparities "national problems," emphasized that these disparities are "pervasive in our health care system," and found that the disparities carry a significant "personal and societal price." The final version of the report, however, contains none of these conclusions.

These changes significantly altered the message of the report. Instead of reinforcing the conclusions of the Institute of Medicine, the *National Healthcare Disparities Report* minimizes the importance and scope of disparities in healthcare.

The Final Version Deletes Most Uses of the Word "Disparity"

The scientists' draft of the executive summary differs markedly from the final version in the use of the word "disparity." The scientists defined "disparity" as "the condition or fact of being unequal, as in age, rank, or degree" and explained that of special importance were "disparities in health outcomes that may be responsive to improvements in health care."⁶ The word appeared in three of the scientists' seven key findings:

1. Inequality in quality persists.
2. Disparities come at a personal and societal price.
3. Differential access may lead to disparities in quality.
4. Opportunities to provide preventive care are frequently missed.
5. Knowledge of why disparities exist is limited.
6. Improvement is possible.

⁵ *National Healthcare Disparities Report: Executive Summary* (Scientists' Draft), 1 (June 2003) (online at www.politicsandscience.org) (hereinafter "Scientists' Draft").

⁶ *Id.* (emphasis added).

7. Data limitations hinder targeted improvement efforts.⁷

In elaborating upon these findings in the executive summary, the scientists used “disparity” or “disparities” over 30 times.

The final version of the *National Healthcare Disparities Report*, by contrast, avoids the use of the word “disparity.” It favors the word “difference,” in part because this term does not imply the need for improvements in health care. The executive summary of the final version explains:

Where we find variation among populations, this variation will simply be described as a “difference.” By allowing the data to speak for themselves, there is no implication that these differences result in adverse health outcomes or imply prejudice in any way.⁸

Consistent with this approach, the words “disparity” and “disparities” appear in none of the final version’s six key findings:

1. Americans have exceptional quality of health care; but some socioeconomic, racial, ethnic, and geographic differences exist.
2. Some “priority populations” do as well or better than the general population in some aspects of health care.
3. Opportunities to provide preventative care are frequently missed.
4. Management of chronic diseases presents unique challenges.
5. There is still a lot to learn.
6. Greater improvement is possible.⁹

In elaborating upon these findings, the final version uses “disparity” or “disparities” twice. In both instances, the words are used to refer to HHS policy on disparities, not the evidence presented in the report.

The Final Version Eliminates the Conclusion That Healthcare Disparities Are “National Problems”

The scientists’ draft and the final version offer radically different assessments of healthcare disparities in the United States. The scientists concluded: “This report

⁷ *Id.* at 4–5.

⁸ Department of Health and Human Services, *National Healthcare Disparities Report*, 2 (Dec. 2003).

⁹ *Id.* at 5.

... confirms that there is significant inequality in [health care] quality in the United States.”¹⁰ The scientists further wrote:

This first report clearly demonstrates that racial, ethnic, and socioeconomic disparities are national problems that affect health care at all points in the process, at all sites of care, and for all medical conditions — in fact, disparities are pervasive in our health care system.¹¹

The final version, however, never calls disparities “national problems.” It drops the finding that “there is significant inequality” in health care in the United States. Instead, the final report states:

This first report finds that, while most Americans receive exceptional quality of health care and have excellent access to needed services, some socioeconomic, racial, and ethnic differences exist.¹²

The final version also describes the state of the evidence as follows: “Despite the high quality of care available, some studies and commentators have suggested that a gap exists between ideal health care and the actual health care that Americans sometimes receive.”¹³

The Final Version Drops Findings on the Social Cost of Disparities and Replaces Them with a Discussion of “Successes”

The scientists’ draft and the final version differ in their treatment of the costs of healthcare disparities. The scientist’s executive summary concluded that “disparities come at a personal and societal price” — including lost productivity, needless disability, and early death.¹⁴ This conclusion mirrored findings by the Institute of Medicine. In March 2002, the Institute of Medicine report *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare* found that “racial and ethnic disparities in healthcare threaten to hamper efforts to improve the nation’s health” and “the costs of inadequate care may have significant implications for overall healthcare expenditures.”¹⁵

¹⁰ Scientists’ Draft, 5.

¹¹ *Id.*

¹² Department of Health and Human Services, *supra* note 8, at 5.

¹³ Department of Health and Human Services, *supra* note 8, at 3 (emphasis added).

¹⁴ Scientists’ Draft, 6.

¹⁵ Institute of Medicine, *Unequal Treatment: Confronting Racial and Ethnic Disparities in Healthcare*, 31 (Mar. 2003)

The final version of the HHS report, however, makes no mention of the costs of disparities to individuals or society. The scientists' conclusion is replaced with a new finding: "Some 'priority populations' do as well or better than the general population in some aspects of health care."¹⁶ The report cites four examples of "successes":

- APIs [Asian/Pacific Islanders] and AI/ANs [American Indians/Alaska Natives] have a lower death rate from all cancers.
- APIs have lower hospitalization rates for complications of diabetes.
- Black and Hispanic patients are more likely to report that their provider usually asks about medications from other doctors.
- Hispanics and APIs have lower rates of hospitalizations from influenza.¹⁷

The discussion in the executive summary includes no additional context for these statements, even when more information is available in the chapters of the report. For example, while American Indians and Alaska Natives have a lower overall death rate from cancer, this may be due to their increased risk of death earlier in life from preventable causes. The summary does not mention that chapter 5 of the report explains that among American Indians and Alaska Natives served by the Indian Health Services, "males can expect to live 6 years less than the average U.S. male and ... females can expect to live 5 years less than the average U.S. female."¹⁸ The chapter continues:

Infant mortality rates ... are 24% higher than the total population. Mortality rates experienced ... are disparate with overall U.S. rates: mortality rates are 67% higher due to alcohol-related causes, 318% higher for diabetes, 180% higher due to accidents, 92% higher due to suicide, and 110% higher due to homicide.¹⁹

Similarly, the final executive summary does not explain that while Black and Hispanic patients are more likely to have doctors who ask about medications from other doctors, this may be due to the fact that Black and Hispanic patients are more likely to lack a regular physician than other patients.²⁰ Physicians who do not know their patients commonly ask about medications prescribed by other doctors.

¹⁶ Department of Health and Human Services, *supra* note 8, at 6.

¹⁷ *Id.*

¹⁸ *Id.* at 176.

¹⁹ *Id.*

²⁰ *Id.* at 126.

By including as a finding that “some ‘priority populations’ do as well or better than the general population in some aspects of health care,” the final report appears to be positing a balance between benefits and problems experienced by racial and ethnic minorities in healthcare. This is a dramatically different presentation than the discussion of social costs of healthcare disparities in the scientists’ draft.

The Final Version Omits Key Examples of Healthcare Disparities

The scientists’ draft of the executive summary included multiple examples of serious racial and ethnic disparities in health care, such as:

- Minorities are more likely to be diagnosed with late-stage breast cancer and colorectal cancer compared with whites.
- When hospitalized for acute myocardial infarction, Hispanics are less likely to receive optimal care.
- The use of physical restraints in nursing homes is higher among Hispanics and Asian/Pacific Islanders compared with non-Hispanic whites.
- Many racial and ethnic minorities and persons of lower socioeconomic position are more likely to die from HIV.²¹

The final version drops all of these examples. Instead, the report highlights “differences” in care that are generally less alarming than those in the scientists’ draft. The examples in the final version include: “Hispanics and American Indians or Alaska Natives are less likely to have their cholesterol checked” and “Rates of admission for conditions that are usually treatable with ambulatory care are generally higher for people who live in low income areas.”²² The final version does mention, however, that blacks and people with lower social economic status have higher death rates from cancer.²³

CONCLUSION

A Special Investigations Division report released by Rep. Waxman in August 2003 found that the Bush Administration repeatedly distorted science to promote a narrow political or ideological agenda. Among the examples of political interference cited in the report were instances of altered web sites, suppressed

²¹ Scientists’ Draft, 5.

²² Department of Health and Human Services, *supra* note 8, at 5.

²³ *Id.*

agency reports, erroneous international communications, and misleading statements by senior Administration officials.²⁴

This report finds further evidence of the politicization of science at HHS. A comparison of the final version of the *National Healthcare Disparities Report* with the draft written by HHS scientists reveals evidence of significant alterations. Changes to the scientists' draft minimized the importance and extent of racial and ethnic disparities in healthcare, undermining efforts to address these problems.

²⁴ Minority Staff, Government Reform Committee, *supra* note 1.